



ORIGINAL ARTICLE

Transgender Youth Readiness for Health Care Transition: A Survey of Youth, Parents, and Providers

Michelle V. Tsai,^{1,†} Laura E. Kuper,^{2,3} and May Lau^{1,4,*}

Abstract

Purpose: The purpose of this study was to identify health care transition (HCT) readiness and skills among transgender youth transitioning gender-affirming care from pediatric to adult providers.

Methods: A convenience sample of youth, 14–21 years old, their parents, and health care providers recruited from a multidisciplinary transgender youth clinic in 2019 completed a modified version of the Got Transition readiness assessment with elements specific to gender-affirming care. Youth assessed their own readiness, parents assessed their child's readiness, and providers assessed their transgender patients' readiness overall.

Results: Twenty-nine youth (mean age 17.0 years), 26 parents, and 5 health care providers participated. Ratings of the overall importance of preparing for HCT were similar across all participant groups, and there were few disagreements on the importance of individual skills included in the readiness assessment. Ratings of overall HCT readiness were similar for youth regardless of age, while parents of younger youth (< 18 years old) reported lower readiness than did parents of older youth. Youth rated their own competence in several skills higher compared with parents or providers, including knowledge of hormone therapy side effects. All groups of participants reported that youth most frequently needed assistance with scheduling appointments and keeping records of health information.

Conclusions: Survey of youth, parents, and providers suggests that youth and parents require additional support to navigate the HCT process, highlighting the importance of ongoing skills assessment and planning.

Keywords: adolescent health; health care transition; quantitative skills assessment; transgender

Introduction

While research has examined the health of transgender youth and benefits of gender-affirming medical treatment, the process of transitioning care from pediatric to adult health care providers has yet to be studied in this population. Transgender youth experience higher rates of depression, suicidal ideation, and other mental health conditions compared with cisgender peers.¹

The period of health care transition (HCT) can result in worsened health for adolescents in general.^{2,3} Among youth with chronic medical conditions, inadequate HCT has been associated with an increased risk of poor long-term health outcomes.^{4–6}

Successful care continuation in the adult health care system is an important aspect of maintaining health for adolescents.

Guidelines in “Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home” from the American Academy of Pediatrics recommend developing an HCT policy for a medical practice, monitoring youth progress in mastering skills needed for HCT, and planning HCT timing with youth and parents.² Knowledge of how to navigate the adult

¹Department of Pediatrics, University of Texas Southwestern Medical Center, Dallas, Texas, USA.

²Department of Psychiatry, University of Texas Southwestern Medical Center, Dallas, Texas, USA.

³Division of Pediatric Endocrinology and ⁴Division of Developmental and Behavioral Pediatrics, Children's Health System of Texas, Dallas, Texas, USA.

[†]Current affiliation: Department of Neurology, Ochsner Medical Center, New Orleans, Louisiana, USA.

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*Address correspondence to: May Lau, MD, MPH, Department of Pediatrics, University of Texas Southwestern Medical Center, 5323 Harry Hines Boulevard, Dallas, TX 75390, USA, E-mail: may.lau@utsouthwestern.edu

health care system should be assessed, including legal changes to health information privacy, consent, and insurance. Although guidelines recommend beginning discussion of HCT at 12–14 years old and assessing skills from 14–18 years old, the structure of an HCT program is meant to address individual needs.

Factors contributing to adolescents' participation in their own health care are described in self-management theory.^{7,8} Self-management refers to an individual's ability to optimize their health through actions such as taking medications without prompting. In the adult health care system, self-management requires further skills such as making appointments, maintaining health insurance, and communicating health needs.

Developing these skills requires setting goals, planning, and reflecting on progress made to change behaviors. For youth, parents often are responsible for or assist with many skills. As youth grow in their ability to self-manage their health care, family members' roles decrease.

Youths' attitude toward HCT is important to assess as part of a self-management framework.^{8,9} Evaluation of transition skills perception among youth and parents has found incongruence, with parents rating youth as less ready to self-manage and rating multiple skills as more important than youth did.^{10,11} Differences in perceived skill competence and importance may portend difficulty acquiring necessary skills for HCT. Including perspectives of parents and providers gives a more complete picture of youth preparedness, potentially highlighting topics needing further discussion. Parents are particularly vital to the gradual shift in responsibility that youth require for a smooth HCT process.

Examination of HCT skills and knowledge acquisition among youth with chronic medical conditions has found some common trends across conditions. Overall, youth self-management skills improve with age.^{11–13} One study of adolescents and young adults, 16–26 years old, with special health care needs (activity-limiting conditions vs. mental health/cognitive impairment) demonstrated that regardless of condition, all youth scored lowest on items regarding health insurance knowledge, including current coverage and maintaining future coverage.¹⁴

A literature review of barriers to developing self-management skills found that youth with chronic medical conditions most frequently needed assistance with medication adherence, health literacy, and appointment scheduling.¹⁵

HCT for transgender youth may differ from recommendations for youth with chronic medical conditions. Gender-affirming care can involve puberty suppression, gender-affirming hormone therapy, and/or surgeries to reflect one's gender identity. In attempting to obtain care, transgender youth face social stigma, a dearth of knowledgeable health care providers, and insurance exclusions.¹⁶

Legal name and gender marker change, in addition to being gender affirming, can reduce an individual's likelihood of experiencing discrimination or harassment.¹⁷ A qualitative study conducted alongside this study found navigating a complex medical system with multiple health care providers to be another barrier to HCT.¹⁸ Insurance coverage difficulties arise for both puberty suppression and procedures such as chest surgery.¹⁹

These problems carry over into adult care, leading to more unmet health needs compared with cisgender patients.^{20,21} Understanding and improving the HCT process for transgender youth provide an opportunity to potentially reduce lifelong health care disparities.

Assessment of HCT readiness to identify skills needing improvement is crucial for preparing youth to navigate the adult health care system and has not been studied among transgender youth who face unique barriers to care, making it unclear how they fare regarding this topic. No tool currently exists to evaluate the specific health needs of transgender youth changing from pediatric to adult health care providers.

The first aim of this study was to identify readiness of transgender youth for HCT using a modified skills assessment with items specific to gender-affirming care. A second aim was to examine differences between youth, parent, and health care provider evaluation of youth competence in and importance of specific skills.

Methods

Participants and procedures

A convenience sample of transgender youth 14–21 years old and parents of transgender youth 14–21 years old were recruited from a multidisciplinary clinic for gender-affirming care in Dallas, TX. Youth recruitment occurred in January through February 2019 during clinic appointments. This study was conducted alongside a qualitative study of barriers and unmet HCT needs for transgender youth using the same participant sample.¹⁸

When patients 18–21 years old attended the clinic without a parent, youth permission was obtained

before recruiting their parent by phone. Health care providers included physicians, nurses, and social workers from the clinic plus several who cared for transgender patients 18–21 years old in adult care settings within the same region.

Consent was obtained from parents for youth 14–17 years old and from youth 18–21 years old. Youth 14–17 years old provided assent to participate. Responses were stored within a secure REDCap database and exported to SPSS 25 for analysis.^{22–24} The University of Texas Southwestern Institutional Review Board approved the study protocol.

Survey measures

Youth and parents independently completed a socio-demographic survey and a modified version of the Got Transition readiness assessment, version 2.0, online using a link sent to their personal e-mail address.²⁵ Along with age and gender identity, the youth socio-demographic survey included items about puberty suppression and gender-affirming hormone therapy, additional physical or mental health diagnoses, and legal name and gender marker changes. The parent sociodemographic survey included items about parents' own assigned sex and gender and their child's health care and legal identification changes.

The Got Transition readiness assessment helps youth evaluate their own readiness and facilitates transition planning.²⁵ This measure was selected because it accompanied a larger toolkit of transition resources that can be used to further develop the HCT process.

As recommended by Got Transition, the authors tailored the measure to include 10 additional items relevant to our specific population of transgender youth. The second and third authors drafted the modified version by identifying skills not currently included but relevant to transgender youth, based on their extensive experience working with this population. The modifications were also reviewed for feedback by two other physicians in the clinic.

For each statement, youth indicated their own competence in the skill using the following response options: yes I know this, I need to learn to do this on my own, someone needs to help me with this, or not applicable. To further assess the applicability of the items to our population, youth indicated the importance of each skill to them using the following response options: important, somewhat important, not important, unsure, or not applicable.

In two additional items, youth rated the importance of preparing to transition to adult care and their confidence in their ability to prepare on a 0–10 scale, with 0 indicating not at all important/confident and 10 indicating very important/confident. Parents answered a parallel version regarding their own child, and health care providers answered a parallel version regarding their transgender patient population.

Statistical analysis

Youth were divided into two groups by age (14–17 years old and 18–21 years old) and parents were divided by their child's age to evaluate for differences in perceived importance of and readiness for transition between those closer to and further from completing HCT. Independent *t* tests were used to analyze youth and parent ratings on 11-point scale items, comparing youth by age group and comparing parents by their child's age group.

Paired *t* tests were used to compare ratings within the subset of youth–parent dyads (i.e., youth and parent from the same family). Chi-square tests were used to compare ratings of youth transition skill competence by participant group (youth, parents, and providers), and Bonferroni pairwise *z*-tests were used to follow-up significant results. McNemar chi-square tests were used to compare youth and parent ratings within the subset of youth–parent pairs.

Responses of needing to learn a skill and needing help with a skill were collapsed for these analyses, as were ratings of important and somewhat important for descriptive purposes. Responses of not applicable or unsure were coded as missing data.

Results

Twenty-nine youth, 26 parents, and 5 health care providers participated in the study. There were 15 youth–parent pairs. Youth demographics can be found in Table 1. Most youth had been assigned female at birth, identified as male, and were white. Additionally, most youth were receiving gender-affirming hormone therapy and had been diagnosed with a mental health condition such as depression or anxiety (Table 2).

Half of the youth 14–17 years old and over 1/3 of youth 18–21 years old were unsure of their insurance status. About half of the youth in both age categories had their legal name changed. More youth ≥ 18 years old than < 18 years old had their gender marker changed on their birth certificate, driver's license, or passport.

Table 1. Youth Self-Reported Sociodemographic Information

Characteristic	Youth (n = 29)
Age, years	17.0
Assigned sex	
Female	69%
Male	31%
Gender identity	
Male	55%
Female	31%
Nonbinary	14%
Race/Ethnicity	
White	76%
Black	10%
Hispanic	7%
Other	7%
Insurance type	
Public	14%
Commercial	41%
Self-pay	0%
Unsure	45%

Age is reported as mean; other values are frequencies. Participants wrote in their gender identity.

Most parents had been assigned female at birth and identified as female. These demographic characteristics held true for health care providers (Table 3). Most providers' transgender patients fell between 14 and 17 years old. All groups reported similar frequencies of medical and mental health comorbidities among transgender youth.

Youth perceptions of readiness for and importance of HCT did not differ significantly between the two age groups (Table 4). Among parents, ratings of the importance of preparing for HCT were similar. However, parents of youth 14–17 years old rated their child's readiness significantly lower than parents of

Table 3. Pediatric Health Care Provider Self-Reported Sociodemographic Information and Patient Characteristics

Characteristic	Pediatric providers (n = 5)
Age, years	42.2
Assigned sex	
Female	60%
Male	40%
Gender identity	
Female	60%
Male	40%
Percent of patients who are transgender	37%
Percent of transgender patients < 14 years old	18%
Percent of transgender patients 14–17 years old	66%
Percent of transgender patients 18–22 years old	14%
Patients with co-occurring medical condition(s)	24%
Patients with co-occurring mental health condition(s)	73%
Gender-affirming treatment	
Patients on puberty suppression	65%
Patients on menstrual suppression	50%
Patients on gender-affirming hormone therapy	90%

Age is reported as mean; other values are frequencies. Providers reported their own age, assigned sex, and gender identity.

youth 18–21 years old ($t(25)=3.1$, $p<0.01$). Within the paired sample of youth and parents, importance and readiness ratings did not differ.

Regarding transition skills (Table 5), youth 14–21 years old rated their own competence regarding two skills higher than both parents and health care providers: knowing hormone therapy side effects ($X^2(2, n=60)=12.1$, $p<0.01$) and considering questions to ask before a medical visit ($X^2(2, n=58)=13.8$, $p<0.01$). Compared with parents, youth rated themselves higher at knowing how to reduce the risk of hormone therapy side effects ($X^2(2, n=60)=6.6$, $p<0.05$). Compared

Table 2. Youth Gender-Affirming Care, Mental/Medical Health History, and Legal Identification Change

Characteristic	Youth (n = 29)
Gender-affirming treatment	
On puberty suppression	34%
On menstrual suppression	41%
On gender-affirming hormone therapy	90%
Co-occurring medical condition(s)	24%
Co-occurring mental health condition(s)	86%
Completed legal name change	48%
Completed gender marker change	
Birth certificate	31%
Driver's license	17%
Passport	28%

Youth reported their own gender-affirming therapy, medical conditions, mental health conditions, completion of name change, completion of gender marker change, and insurance.

Table 4. Ratings of Care Transition Importance and Readiness by Youth, Parents, and Health Care Providers

Participant group	Importance rating (mean, SD, range)	Readiness rating (mean, SD, range)
Youth < 18 years old	6.8 ± 2.1 (3–10)	4.5 ± 3.1 (0–10)
Youth ≥ 18 years old	5.9 ± 3.1 (0–10)	4.8 ± 2.7 (0–8)
Parents of youth < 18 years old	4.4 ± 3.6 (0–10)	2.7* ± 2.3 (0–7)
Parents of youth ≥ 18 years old	6.5 ± 3.0 (0–10)	6.3* ± 3.6 (0–10)
Health care providers	8.6 ± 2.1 (5–10)	5.4 ± 1.8 (3–8)

Each participant rated the importance of care transition and youth readiness for care transition on an 11-point scale, with 0 meaning not important/not ready and 10 meaning very important/very ready. SD is included. Range is given in parentheses. The difference in mean parent ratings of youth readiness was statistically significant, denoted by asterisks ($p<0.01$).

SD, standard deviation.

Table 5. Transition Skills Survey Responses of Youth, Parents, and Health Care Providers

Skill	Yes, I know this	Yes, my child knows this	Yes, my patients know this
Know own medical needs	83%	74%	40%
Can explain medical needs to others	72%	74%	20%
Know allergies to medicines and prohibited medicines (if applicable)	94% ^a	95% ^b	20% ^{a,b}
Know what to do in case of medical emergency	79%	74%	40%
<i>Know name and dose of hormone therapy</i>	68%	77%	80%
<i>Administer own shots (if applicable)</i>	83%	87%	80%
<i>Know supplies needed to give injections (if applicable)</i>	61%	80%	40%
<i>Know hormone therapy side effects, including those needing urgent medical attention</i>	93% ^{a,c}	56% ^c	40% ^a
<i>Know how to reduce risk of hormone therapy side effects</i>	75% ^c	41% ^c	60%
<i>Know the long-term hormone therapy plan</i>	61%	67%	60%
<i>Know names and doses of psychiatric medicines (if applicable)</i>	76%	81%	40%
<i>Know pharmacy location and refill process</i>	59%	52%	40%
<i>Know where to get blood drawn</i>	80% ^a	65%	20% ^a
<i>Know information monitored by blood work</i>	46%	37%	0%
Know or can find medical office's phone number	69%	63%	20%
Make own medical appointments	8%	27%	0%
Consider questions to ask before an appointment	92% ^{a,c}	59% ^c	20% ^a
Know how to complete medical forms	55%	59%	20%
Know how to get referrals to other providers	46%	27%	0%
Carry important health information daily (e.g., insurance card, allergies, medications, emergency contact information, medical summary)	45%	35%	20%
Keep records of own medical information	41%	21%	0%
Have a copy of the current plan of care	32%	26%	20%
Understand how health care privacy changes at age 18	76% ^a	59% ^b	0% ^{a,b}
Have discussed change in health care decision-making at age 18 with family	67%	59%	80%

(continued)

Table 5. (Continued)

Skill	Yes, I know this	Yes, my child knows this	Yes, my patients know this
Can explain how own customs and beliefs affect health care decisions	84%	91%	50%
Have a plan to keep health insurance after age 18 or older	48%	62% ^b	0% ^b

Youth ($n=29$), parents ($n=26$), and health care providers ($n=5$) surveyed responded to these statements as youth knowing the skill, needing to learn or needing help with the skill, or not applicable (coded as missing).

Skills added by the authors to the existing Got Transition assessment are italicized.

^aSignificant difference between youth and health care providers ($p < 0.05$).

^bSignificant difference between parents and health care providers.

^cSignificant difference between youth and parents.

with health care providers, youth rated themselves higher at knowing where to have blood work done ($X^2(2, n=60) = 7.1, p < 0.05$).

Parents rated confidence in youth planning for insurance after turning 18 years old higher than health care providers ($X^2(2, n=60) = 6.4, p < 0.05$). There were two skills that health care providers rated youth competence lower than youth or parents: knowing allergies ($X^2(2, n=43) = 10.6, p < 0.01$) and understanding how health care privacy changes at 18 years old ($X^2(2, n=61) = 10.6, p < 0.01$). Within youth–parent pairs, no significant differences were found.

Youth, parents, and health care providers rated youth knowledge of gender-affirming hormone therapy similarly on all aspects besides side effects. All groups reported a low frequency of youth keeping records of their own medical information and scheduling their own appointments. The item assessing the ability to discuss how customs and beliefs affect health care decisions received the most “not applicable” responses (24.6%).

Twenty-four of 26 skills were rated as important or somewhat important by 95% or more participants. Knowing the information monitored by blood work and understanding how health care privacy changes at 18 years old were rated as important or somewhat important by 93% of participants.

Discussion

To our knowledge, this is the first study to evaluate the readiness of transgender youth for transitioning

care from pediatric to adult health care providers. The first aim of this study was to evaluate HCT readiness among transgender youth using an assessment tailored to this population. Readiness rating by all groups was around the middle of the 11-point scale except for parents of youth < 18 years old, who indicated lower readiness for HCT among their children compared with parents of older youth. Youth rated their own readiness for HCT similarly regardless of age.

The second aim of this study was to examine differences between youth, parent, and health care provider perceptions of youth competence in and importance of skills. Youth rated themselves as more competent in several skills related to gender-affirming hormone therapy and communication than parents or providers. No differences were found in ratings of skills within the subgroup of youth–parent pairs, suggesting that discrepancies between individual youth and their parents may be small. However, this may be driven by the small sample size.

All groups agreed that youth most needed assistance with scheduling appointments and keeping records of their own medical information. Youth, parents, and providers generally agreed on the importance of all assessment items.

These results are consistent with findings among adolescents with and without chronic medical conditions that suggest low readiness for HCT. The 2019–2020 National Survey of Children's Health found that over 3/4 of youth with special health care needs and 4/5 of those without medical conditions did not receive services needed for HCT.²⁶

Two studies of HCT readiness in youth–parent dyads with mean youth age around 17 years had conflicting results, with one study finding that parents rated skills more important than youth did and the other study finding parent–youth concordance regarding transition readiness.^{10,27} For the latter study, perceived readiness increased with youth age, which was noted among parents, but not youth, in our sample.

Transgender youth < 18 years old and their parents may require more support preparing for HCT based on incongruity in their confidence and skill competence ratings. There are multiple possible explanations for this. Younger youth may not have considered HCT as much as older youth. Youth could be overconfident in their own abilities, while parents and health care providers could be underconfident.

There could also be differing perceptions of criteria for knowing versus needing assistance with a skill. Dis-

cussing HCT skills during appointments may provide clarity regarding individual patient readiness. A qualitative study of the same sample describes differing perceptions of youth, parents, and health care providers regarding youth self-management ability in further detail.¹⁸

Given that roughly half of the youth were uncertain about their insurance type and plan for continued coverage as an adult, transgender youth may need further guidance on the financial aspects of health care, especially as transgender patients are known to face more financial barriers to care relative to the general population.²⁸ The cost of gender-affirming care can be affected by insurance coverage, deductibles or copays, and policy exclusions.

Additionally, consistent with the higher rate of mental health conditions among transgender people, 83% of youth self-reported having a mental health condition. Changing multiple health care providers during HCT can make the process more complex, and mental health difficulties can be a barrier to care by limiting patients' ability to participate in HCT.^{2,29} Highlighting the importance of continued mental health care and multidisciplinary collaboration should be part of HCT preparedness for transgender youth.

Deficiencies in transition skills among transgender youth are similar to those among other youth populations. All three participant groups agreed that youth most need assistance with scheduling appointments and keeping their own health records. This matches prior findings that youth with chronic medical conditions frequently need assistance with making appointments.¹⁵ Two other common issues among youth with chronic medical conditions are medication adherence and health literacy.

While most transgender youth in this study reported knowing their psychiatric medications, hormone therapy, and how to administer injections if necessary, slightly less than half reported knowing what information their blood work monitors. Parents gradually increasing youth participation in these activities could boost readiness and confidence among youth and parents. Transgender youth, parents, and health care providers have reported a desire for such graded increase in youth responsibility with a timeline.¹⁸ For example, youth could take the initiative to schedule their next appointment beside their parent. A similar process could be applied to requesting medication refills or asking questions of health care providers.

Limitations

The generalizability of this study's results may be limited by its small sample size from a single clinic, which included mostly white and transgender male youth. Additionally, this study evaluated perceptions of skills, which may differ from the ability to perform skills, and did not obtain youth feedback regarding transition skills included in the assessment, which could further strengthen the assessment's relevance to this population. Future studies could evaluate the ability to complete skills through observation, tracking of behaviors, or knowledge assessments.

Validation of the readiness assessment is also needed, which may identify skills most predictive of successful HCT. The Got Transition toolkit associated with the assessment used in the present study was developed to synthesize best practices and research within the field of HCT. While the readiness assessment tool is not currently validated, several studies have documented improvements in the HCT process after implementing components of the Got Transition toolkit.^{30–32}

Another commonly used tool is the Transition Readiness Assessment Questionnaire (TRAQ). Several cross-sectional studies have demonstrated good reliability and internal validity of the TRAQ.^{14,33} However, one study found that the TRAQ did not predict transition outcomes or time to transition.³⁴ Lack of external validation has been identified as a concern across existing readiness assessments.^{35–37}

Repeated evaluation of transition skills over time is recommended for successful HCT and has been found to increase confidence and knowledge of skills.^{2,38} Collection of such data from both youth and parents may reveal incongruities in need of further discussion and planning.

Conclusions

This study presents evidence regarding transgender youth readiness for HCT. All three groups rated youth overall preparedness for the process similarly, while parents of youth <18 years old reported lower transition readiness of their children. Youth, parents, and health care providers generally agreed on the importance of the skills assessed, which were modified to include items specific to gender-affirming care. Youth most needed assistance with scheduling appointments and keeping records of health information.

Early consideration of HCT preparedness is likely to better provide youth with the skills and knowledge necessary for a smooth HCT.

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Authors' Contributions

M.V.T. was involved in methodology, investigation, data curation, investigation, writing—original draft, writing—reviewing and editing, and visualization. L.E.K. was involved in conceptualization, methodology, formal analysis, and writing—reviewing and editing. M.L. was involved in funding acquisition, conceptualization, methodology, and writing—reviewing and editing.

Disclaimer

The data for this study were extracted from a larger study examining transition of transgender youth. The qualitative results from this study were published in *LGBT Health*.¹⁸

Author Disclosure Statement

No competing financial interests exist.

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Abbreviations Used

HCT = health care transition
SD = standard deviation
TRAQ = Transition Readiness Assessment Questionnaire